



POINTERS FOR PLANNING
IN
MENTAL RETARDATION

NATIONAL ASSOCIATION FOR RETARDED CHILDREN, INC.
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POINTERS FOR PLANNING
IN
MENTAL RETARDATION

Prepared by the
National Association for Retarded Children
as an Aid to Persons and Agencies Responsible for
Comprehensive State Planning.

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TABLE OF CONTENTS

	Page
Why "Pointers for Planning in Mental Retardation"	
Has Been Prepared	1
"Blue Prints for Action" Is the Goal	1
"Timing" Is Extremely Important	2
What Is a "Factual and Forthright" Report ?	3
The Report of the President's Panel Is a Gold Mine	
of Information and Ideas	4
Where Else You Can Go for Help	5
Professional and Governmental Roles in Mental	
Retardation	7
The Purpose of the Comprehensive State Planning	7
Program Areas To Be Included in the	
Comprehensive Planning:	
Education	9
Employment	10
The Law	11
Mental Health	12
Public Awareness	13
Public Health	14
Recreation	15
Residential Care	15
Vocational Rehabilitation	17
Welfare	18

	Page
Appendix A. State Legislative Sessions and Governors' Terms of Office	20
Appendix B. Extracts from the Report of the Minnesota Governor's Advisory Committee on Mental Retardation	23
Appendix C. Recommendations from the Report of the President's Panel on Mental Retardation	28
Appendix D. Volunteer Leadership and Staff of the National Association for Retarded Children to Whom Inquiries May Be Directed	41
Appendix E. National Association for Retarded Children Roster of State Presidents and Executives	43
Appendix F. Regional Offices of the U.S. Department of Health, Education, and Welfare. . . .	50

Why "Pointers for Planning in Mental Retardation" Has Been Prepared

Nearly all of the States have qualified for Federal funds to help pay for comprehensive planning in mental retardation under a grant program approved by Congress in 1963.

Agencies to administer the grants have been designated by the Governors. Provisions have been made for advisory and other groups to participate in the work, and appointments of professional staff are being made.

The planning activity will result in important advances in the attack on mental retardation. Courses of action will be charted that will point the way for better services and better programs of prevention. Because the planning process is the first step, it is important that it be sound.

The National Association for Retarded Children is pleased that this activity is now underway and that throughout the Nation representatives of State and Local Associations for Retarded Children have been invited to participate in the planning operation.

These "Pointers for Planning" have been prepared as a guide to all who are participating in this undertaking. While conditions and needs vary greatly from State to State, the suggestions on the following pages will be helpful regardless of local problems.

"Blue Prints for Action" Is the Goal

Congress intended that the grants for comprehensive planning would result

in "blue prints for action" in combating mental retardation. Keeping this objective in mind will help to shape the kind of final report that will have the greatest impact in your State.

Here are some tips:

Be sure that out of your effort comes a report that will justify public support.

Make it factual and forthright.

Emphasize policies and program recommendations.

Establish goals.

Do not get lost in a maze of detail --do not try to plan budgets or select sites.

Maintain objectivity at all times and avoid subordination to any single governmental agency or department.

Timing is extremely important. Do not get bogged down.

"Timing" Is Extremely Important

Why is "timing" so important ?

Consider these events:

In 1961 President Kennedy appointed a Panel of experts to prepare a national plan to combat mental retardation.

In 1962 the Panel made its report.

In 1963 Congress responded with major new laws. In addition, the White House Conference on Mental Retardation was held.

In 1964 the expanded and new programs are being launched and comprehensive planning is underway.

What about 1965 ? Will the momentum be sustained? What needs to be done to put this program into high gear ? Will more retarded individuals receive better services?

Take a look at Appendix A, which was prepared for us by the Council of State Governments. It shows for each State when the legislature convenes and when the term of office of the Governor expires. Find out when your report ought to be available in your State for consideration by all concerned -- then keep an eye on the calendar!

Remember that the President's Panel produced an excellent report in just one year -- October 1961-October 1962. Furthermore, it came out in time to be included in the Administration's 1963 legislative and budgetary programs. If the Report had been delayed only one month it is doubtful that the new laws enacted by Congress in 1963 would have been in existence today.

Be sure to pay special attention to the legislative deadlines in your State.

Give the Governor, the legislature, and the people a document on which they can act and at a time that they can use it.

What Is a "Factual and Forthright" Report ?

The kind of report that will be most useful will vary from State to State. It may be helpful, however, for you to know about prior State planning efforts. Two good reports were prepared in the State of Washington in 1961 and in Minnesota in 1962.

Fifth copies of each of these two reports have been distributed by NARC to the staff person responsible for comprehensive planning in each State. You will want to familiarize yourself with both reports. You can get an idea of the content of the Minnesota report at once by referring to Appendix B, which contains those sections of the report entitled A Frame of Reference, "Elements of a Total Program," and "Responsibility for Community Services for the Mentally Retarded."

The Report of the President's Panel Is a Gold Mine of Information and Ideas

One of the purposes of the comprehensive planning grants was to provide, with Federal assistance, a means for encouraging all of the States to initiate systematic follow-up action on the Report of the President's Panel.

The Panel's Report contains a great deal of background information on clinical and social services, education, residential care, public awareness and other subjects. The part of the Report on organization of services, planning, and coordination is especially pertinent to the work of the State planning bodies.

All of the Panel's 95 recommendations are reproduced in Appendix C. Those requiring State and Local action have been starred. You are urged to study these recommendations carefully to determine how they can best be applied in your State.

The way in which the President's Panel proceeded with its assignment also

should be helpful to the State planning groups. The people who made up the Panel were actively involved and participated in the production of the final report. There were no figureheads or people who did not work. Each had an assignment and was active in obtaining information.

While the Panel's Report was being prepared the continuing interest of the President was fostered. This interest was maintained by regular reports to key staff of the President. Agency officials who soon were to make legislative and budgetary recommendations also were kept informed. Thus they were able to give thought to the manner in which the recommendations could be integrated in broadening programs of the administration. It is very important to keep the Governor and his staff within each State informed of what is transpiring during the planning process.

Serious attention was given to the mechanism for implementation of the recommendations. The value of the State plan likewise will be determined by the degree of momentum which is generated and which will continue beyond the planning cycle.

Where Else You Can Go for Help

In the preparation of your report you may want help. Here are some of the places to which you can turn:

1. There are great resources of information and knowledge within the National Association for Retarded Children. Do not hesitate to call upon the professional staff and volunteer leadership of the National Association. While they

may not know your State problems intimately, they can suggest sound policies, publications, and other sources of information. In Appendix D, you will find a list of the persons who can be helpful to you and their areas of responsibility.

2. There also are valuable sources of help in the State Associations for Retarded Children in 49 States. The name and address of each State Association President (and the Executive Director or Secretary, if there is one) is included in Appendix E. Write to the State Association President of your State to secure help on subjects requiring specific knowledge of local conditions. Do not hesitate to share your needs and problems with persons at the State ARC level. Our goal is to help retarded persons through improved services.

3. In securing facts on particular subjects within your State do not hesitate to direct inquiries to appropriate State officials. Since most of the State agencies are represented on the State planning body, they can be asked to secure statistics and other data from their agencies.

4. Federal agencies also can be used as sources of information. In Appendix F, is a listing of the regional offices of the Department of Health, Education and Welfare. Within the regional offices are staff persons who have knowledge of the various Federal programs relating to mental retardation.

A word of caution. Do not expect to get every last pertinent fact or you will be immobilized. In many instances you will be able to reach accurate judgements and make sound recommendations even though you have not been able to complete a precise measurement of existing services or gaps.

Professional and Governmental Roles in Mental Retardation

In the jacket in the back cover of this publication is a booklet entitled "Professional and Governmental Roles in Mental Retardation." This booklet sets forth in considerable detail the objectives of comprehensive State planning and the need for continued program coordination in the future.

Your attention is invited especially to the section of this booklet (pages 16, 17, and 18) that deal with "The Future Patterns of Organization." In this section it is emphasized that from the planning process and the new and enlarged Federal-State programs will come great forward steps in defining goals and in strengthening programs of prevention, services, and care. While there will be differences among the States as they make program and administrative decisions, these tasks must be carried forward by those agencies of government with responsibilities in education, health, welfare, rehabilitation and employment. Out of the planning process also should come a greater awareness of the relationship of the tasks of each agency to the total needs of retarded persons. Provision also must be made for ways in which to secure a continuum of services and a proper coordination of the efforts of all.

Additional copies of this booklet may be secured (at 25 cents per copy) from the National Association for Retarded Children. Also included in the jacket is a copy of the NARC booklet, "Facts on Mental Retardation." (additional copies may be obtained at 10 cents each.)

The Purpose of the Comprehensive State Planning

The law states that the purpose of the planning grants is to assist the

States to "plan for and take other steps leading to comprehensive State and community action to combat mental retardation." (P.L. 88-156, Sec. 1701)

The Federal funds may be used by a State:

"....to determine what action is needed to combat mental retardation in the State and the resources available for this purpose, to develop public awareness of the mental retardation problem and of the need for combating it, to coordinate State and Local activities relating to the various aspects of mental retardation and its prevention, treatment, or amelioration, and to plan other activities leading to comprehensive State and community action to combat mental retardation." (Sec. 1702)

To secure a grant the State must submit an application that "indicates the manner in which provision will be made to assure full consideration of all aspects of services essential to planning for comprehensive State and community action to combat mental retardation," including services in the fields of education, employment, rehabilitation, welfare, health, and the law, and services provided through community programs and institutions for the mentally retarded.

Program Areas To Be Included in the Comprehensive Planning

On the following pages is a statement on each of these fields followed by a

series of suggestive questions that you will find pertinent to the planning operation.

Education

The provision of educational opportunities for retarded children of school age is the responsibility of the public school systems. Educational programs for the retarded should be such that they fit the needs and abilities of each individual child and help him to develop to his fullest potential. Teachers of the retarded should be highly qualified individuals who are specially trained to work with the retarded. It is the responsibility of State Departments of Education or Public Instruction to establish standards, provide leadership and professional guidance and grant financial aid to public school systems in developing day school programs for the retarded throughout the State.

Are public school classes available for retarded children of school age? Are they conveniently located? Are classes lacking in some places? Is appropriate transportation provided? Are there cooperative school district arrangements ?

Is there provision for adequate State support for the excess cost of special classes ? For transportation to consolidated classes ?

Is special education adequately provided for in the State agency ?

Are qualified teachers selected for classes for the mentally retarded? Is there a shortage of qualified teachers ? If so, what is being done to overcome the shortage? Are the education programs within the State's colleges and universities meeting the need for teachers and supervisory personnel ?

Are there realistic requirements for admission to special classes? Is there proper provision for emotionally disturbed children -- or are they put in classes for the mentally retarded? Is there counseling available to parents ?

Is special education part of a continuum that is related to vocational education and vocational rehabilitation? Is there provision for work-school programs and for school sheltered workshop programs ?

Are there adult education programs for the retarded?

Are facilities for the retarded of comparable quality to other educational facilities ?

Employment

A good program of employment services can help the mentally retarded locate and be placed in employment situations commensurate with their abilities. The program should provide the professional services needed for evaluation, counseling, recruitment, and placement.

Are there evaluation programs to assist those who require special placement services to obtain the best possible job opportunities?

Are there adequate means by which job opportunities can be created in the communities ?

Are the retarded carefully prepared for meeting the employer before job placement?

Is the employer given an advance understanding of the mentally retarded and the contribution they can make as employees ?

Are retarded persons given opportunities for employment in the wide range of jobs in which they have been found to be capable of performing ?

Are job opportunities for the handicapped adequately publicized?

Are there follow-up counseling services to assist the retarded person after he has obtained employment ?

The Law

The President's Panel recommends a thorough review of civil and criminal law and regulations as they relate to the mentally retarded, including such subjects as guardianship, commitment, and court procedures on competency. There should also be a review of State laws and regulations in the various program areas -- education, welfare, health, etc. -- to provide for modern terminology and new concepts of treatment and care.

While it is doubtful that many of the State planning bodies will be fully equipped to complete a detailed review of the law and legal procedures leading to recommendations for change during the life of the planning body, be sure that the necessity for such a review is emphasized.

Has provision been made for appointment of a study commission in your State to review all pertinent aspects of the law ?

Has your review of State programs suggested areas of the law and regulations that should be revised ?

Is a satisfactory codification of relevant laws in existence ?

In addition to the report of the "Task Force on the Mentally Retarded and the Law", there is now available "A Check List On State Laws and Regulations Affecting the Mentally Retarded." Both documents are available from the Superintendent of Documents, Washington, D.C. 20402. (20 cents for the Task Force Report and 25 cents for the Check List.)

Mental Health

Some mentally retarded persons also are emotionally disturbed. Other persons appear to be retarded as a result of mental illness. Parents and siblings of retarded children may need counseling and assistance in coping with the mental retardation problem. Mental health departments should have identifiable programs to assist mentally retarded persons and their families with the associated emotional problems.

Does the mental health department now have programs which provide psychiatric care and treatment for mentally ill retarded persons ?

Are these programs conducted in close cooperation with programs of education, welfare, recreation, rehabilitation, and residential care?

Are emotionally disturbed mentally retarded persons (and their families, when necessary) served by professionally trained persons--psychiatrists, psychiatric social workers, psychiatric nurses, etc ?

Does the mental health department provide consultation and assistance to the diagnostic and evaluation clinics supported by the public health departments ?

Are mental health diagnostic facilities equipped to serve retarded persons ?

Public Awareness

Public awareness provides the foundation for community support so necessary for the success of mental retardation programs. It plays a key role in shaping the attitudes of legislators, administrators, and workers in the pertinent fields. One major purpose of the comprehensive planning is to enhance public understanding. In achieving the goal of better public awareness of the problem, the interest of professional and community leaders should be enlisted.

Is provision being made for the publication of the comprehensive State plan? Will it be given wide distribution to the public, including interested business, fraternal, civic, labor, and religious groups?

Are the State agencies responsible for various mental retardation programs issuing meaningful reports to the public on program objectives and accomplishments ?

Is the public being informed about the progress in planning and the people contributing to the success of the operation?

Public Health

Public health services should be available in sufficient quantity and quality to prevent mental retardation to the greatest extent that medical knowledge makes possible, to provide complete diagnosis and evaluation in all communities, and to ameliorate as much as possible the effects of retardation and any associated physical problems.

Does the health department have a vigorous approach to the problem of prevention? Is it mobilizing for this purpose its programs of maternal and child health, accident prevention, public health nursing, nutrition and radiological health?

Are special projects to provide maternal and child care to low income families being supported?

Are there programs of screening and detection? Are there a sufficient number of diagnostic clinics and are they accessible to persons in all parts of the State?

Are there major gaps in the medical services available to the mentally retarded? Are the retarded adequately included in programs of school health, crippled children, and well-baby clinics? Are genetic counseling services available? Are adequate clinical services available to the adult retarded?

Recreation

Mentally retarded persons derive important physical, social, and educational benefits from participation in appropriate recreational activities. State and community programs should be available to retarded persons and modified when necessary to meet their special needs. There should be cooperative action between public and private agencies to promote recreation programs.

Do recreation programs exist to meet the special needs of the retarded?

Are there recreational programs for the homebound and those in residential care facilities?

Is State and local governmental support provided?

Are good recreational facilities available?

Is trained manpower available?

Residential Care

Residential facilities should be available to serve all retarded children and adults who are in need of long or short term care. They should be equipped to provide for the therapeutic needs of each individual. Institutions are one element in the total spectrum of services. Residential care should be community-based and should be limited to those whose specific needs can best be met by this type of service.

Is each institution in the State basically therapeutic in character or mainly custodial? Does its program seek to reduce or eliminate as many symptoms as

possible, emphasize the maximum realization of the individual's potential, and wherever possible, prepare the retarded for living in the community ?

Are the facilities large and isolated or are they accessible, community-based, and linked with appropriate medical, educational, and welfare programs in the communities ? Are the buildings satisfactory or antiquated ? Are they overcrowded ? Is a building program of smaller facilities needed ?

Are there waiting lists ? Are provisions made for periodic evaluation of individuals on the list to determine continued need for residential care ?

Are the State institutions adequately financed ? Are allowances sufficient for staff, food, clothing, and other expenses of institutional maintenance ?

Is each facility staffed with sufficient numbers of qualified physicians, nurses, teachers, attendants and other personnel ? Are there appropriate in-service training programs for these personnel ?

Does the administration have outside affiliations with medical schools, vocational rehabilitation centers, research projects and other activities that will serve to keep it abreast of current developments ?

Note: The planning agency should have at hand two recent publications that deal with institutional standards in detail--(1) Standards for State Residential Institutions for the Mentally Retarded, American Association

on Mental Deficiency, January 1964; and (2) A Survey and Study of State . Institutions for the Mentally Retarded in the United States, National Association for Retarded Children, 1963.

Vocational Rehabilitation

Vocational rehabilitation is the means by which the handicapped can be prepared for remunerative employment to the fullest extent of their capabilities. Rehabilitation services increase the skills of retarded persons and thus make it possible for them to take advantage of a wider range of job opportunities.

Are vocational rehabilitation services available ?

Are school-work experience programs in existence?

Are there on the job training programs ?

Are there a sufficient number of sheltered workshops ?

Is the State using all available Federal grant funds for vocational rehabilitation services?

Are vocational rehabilitation services available to retarded persons in residential institutions?

Are the State agencies adequately staffed to provide the needed counseling and other services?

Is there adequate case finding?

Are the communities sufficiently aware of the rehabilitation services available to retarded persons?

Welfare

Welfare departments provide services to neglected and dependent children, the aged, the totally disabled, and others in difficulty. The services provided to these groups include financial assistance, homemaker services, foster care placement, guardianship, and protective services. Many mentally retarded persons and their families may need these services. It is important that these services not only be available to them, but that they be organized and offered in such a way as to meet their special needs.

Any advance made in the campaign against mental retardation will directly benefit a significant proportion of the people served by these agencies. While some State agencies have undertaken program responsibilities for the mentally retarded, many more seem unaware of the impact of mental retardation on their caseloads and have made a limited or a reluctant response to this problem. In comprehensive planning there is a unique opportunity to promote an appreciation of the welfare implications for the problem and to chart a course for program development and for cooperation with other agencies.

Does your welfare department have identifiable services for the mentally retarded? Is there adequate staff to handle this problem under each of the areas of program services?

Do existing welfare programs serve the mentally retarded who may now

be eligible ? Do present regulations and practices discriminate against the mentally retarded?

Are welfare services related in a positive manner with employment, rehabilitation, vocational education, health, residential care, and other services to reduce dependency and protect the handicapped ?

Are there good programs of case finding to locate and provide social services to the retarded and their families ?

Are welfare programs providing information and referral services, financial assistance, counseling services and protective services in order to meet the needs of the retarded and their families ?

Are there child placement programs for those requiring suitable substitute homes as well as for the return of the child to his own home and community?

Does your welfare department seek to coordinate clinical and program services for the retarded individual in the community in order to obtain maximum development of the child?

Are there day care programs available and are they suitably licensed and supervised?

APPENDIX A

STATE LEGISLATIVE SESSIONS AND GOVERNORS' TERMS OF OFFICE
AS PREPARED BY THE COUNCIL OF STATE GOVERNMENTS

STATE	LEGISLATIVE SESSIONS CONVENE			EXPIRATION DATE OF GOVERNOR'S TERM
	DAY	MONTH	YEAR	
Alabama	1st Tues.*	May	Odd	January, 1967
Alaska	4th Mon.	January	Annual	December, 1966
Arizona	2nd Mon.	January	Annual	January, 1965
Arkansas	2nd Mon.	January	Odd	January, 1965
California	Odd Mon. after Jan. 1st Even 1st Mon.	January February	Annual**	January, 1967
Colorado	Wed. after 1st Tues.	January	Annual**	January, 1967
Connecticut	Wed. after 1st Mon.	January	Odd	January, 1967
Delaware	Odd 1st Tues. Even 1st Tues. Tues. after 1st Mon.	January February April	Annual**	January, 1965
Florida	Tues. after 1st Mon.	April	Odd	January, 1965
Georgia	Odd 2nd Mon. Even 2nd Mon.	January January	Annual	January, 1967
Hawaii	Odd 3rd Wed. Even 3rd Wed.	February February	Annual**	December, 1956
Idaho	Mon. after Jan. 1st	January	Odd	January, 1967
Illinois	Wed. after 1st Mon.	January	Odd	January, 1965
Indiana	Thurs. after 1st Mon.	January	Odd	January, 1965
Iowa	2nd Mon.	January	Odd	January, 1965
Kansas	Odd 2nd Tues. Even 2nd Tues.	January January	Annual**	January, 1965
Kentucky	Tues. after 1st Mon.	January	Even	December, 1967

*Legislature meets quadrennially on second Tuesday in January after election for purpose of organizing.

**Budget sessions held in even-numbered years, except in Louisiana.

-2-

STATE	LEGISLATIVE SESSIONS CONVENE			EXPIRATION DATE OF GOVERNOR'S TERM
	DAY	MONTH	YEAR	
Louisiana	Even 2nd Mon. Odd 2nd Mon.	May May	Annual**	May, 1968
Maine	1st Wed.	January	Odd	January, 1967
Maryland	Odd 1st Wed. Even 1st Wed.	January February	Annual**	January, 1967
Mass.	1st Wed.	January	Annual	January, 1965
Michigan	2nd Wed.	January	Annual	January, 1965
Minn.	Tues. after 1st Mon.	January	Odd	January, 1967
Miss.	Tues. after 1st Mon.	January	Even	January, 1968
Missouri	Wed. after January 1st	January	Odd	January, 1968
Montana	1st Mon.	January	Odd	January, 1965
Nebraska	1st Tues.	January	Odd	January, 1965
Nevada	3rd Mon.	January	Odd	January, 1967
New Hampshire	1st Wed.	January	Odd	January, 1965
New Jersey	2nd Tues.	January	Annual	January, 1966
New Mexico	2nd Tues.	January	Odd	January, 1965
New York	Wed. after 1st Mon.	January	Annual	January, 1967
North Carolina	Tues. after 1st Mon.	February	Odd	January, 1965
North Dakota	Tues. after 1st Mon.	January	Odd	January, 1965
Ohio	1st Mon.	January	Odd	January, 1967
Oklahoma	Tues. after 1st Mon.	January	Odd	January, 1967
Oregon	2nd Mon.	January	Odd	January, 1967
Penn.	1st Tues.	January	Annual**	January, 1967

**Budget sessions held in even-numbered years, except in Louisiana

STATE	LEGISLATIVE SESSIONS CONVENE			EXPIRATION DATE OF GOVERNOR'S TERM
	DAY	MONTH	YEAR	
Rhode Island	1st Tues.	January	Annual	January, 1965
South Carolina	2nd Tues.	January	Annual	January, 1967
South Dakota	Odd Tues. after 3rd Mon. Even Tues. after 1st Mon.	January January	Annual	January, 1965
Tenn.	1st Mon.	January	Odd	January, 1967
Texas	2nd Tues.	January	Odd	January, 1965
Utah	2nd Mon.	January	Odd	January, 1965
Vermont	Wed. after 1st Mon.	January	Odd	January, 1965
Virginia	2nd Wed.	January	Even	January, 1966
Washington	2nd Mon.	January	Odd	January, 1965
West Virginia	Odd 2nd Wed. Even 2nd Wed.	January January	Annual**	January, 1965
Wisc.	2nd Wed.	January	Odd	January, 1965
Wyoming	2nd Tues.	January	Odd	January, 1967
Guam				January, 1967
Puerto Rico	2nd Mon.	January	Annual	January, 1965
Virgin Islands				Term Indefinite

**Budget sessions held in even-numbered years, except in Louisiana

APPENDIX B

Extracts from the Report of the Minnesota Governor's Advisory Committee on Mental Retardation

A Frame of Reference

The committee has found it useful to develop a general frame of reference within which the various facets of programs for the retarded might be considered. The following statements summarize the general point of view taken by the committee. ¹

1. The Mentally Retarded are Entitled to Opportunities for Maximum Development of Their Potentialities. Services to the retarded should be an integral part of total state and community efforts to provide for the development of all its citizens.

2. The Integrity of the Family Unit Should Be Preserved Whenever Possible. This suggests that services for the retarded should be provided at the family and community levels whenever possible.

3. It is Desirable for the State to Assume Leadership in the Development of Comprehensive Community Programs, but with Responsibility Left With Community Agencies, both Public and Private, for Actual Administration of Most Service Aspects of the Programs. The State must take major responsibility for some matters, such as research and training. In most areas of community programming, however, State function should be restricted to leadership, financial aid, determination of standards and consultant services.

¹Adapted from William I. Gardner & Herschel W. Nisonger, American Association on Mental Deficiency, A Manual on Program Development, monograph supplement to the American Journal on Mental Deficiency, Vol. 66, No. 4, January 1962.

4. Although the Chief Responsibility for Providing Programs for the Mentally Retarded Should Rest with Public (Governmental) Agencies, Voluntary Agencies Should Assume a Vital Role in This Endeavor. The valuable contributions made by voluntary organizations in Minnesota should be recognized and encouraged. Public agencies should advise and consult with voluntary groups, so as to strengthen and coordinate the total resources of the State.

5. Emphasis in the State Program Should be Given to Both Primary and Secondary Prevention of Mental Retardation. By primary prevention is meant prevention of conditions which result in mental retardation. Efforts which serve to lessen the consequences of intellectual retardation, once it has occurred, are termed secondary prevention.

6. State Residential Institutions for the Mentally Retarded Should be Viewed as Modern Treatment, Care and Training Centers, with the Goals of Providing for the Maximum Development of Each Resident Person and Return to Community Placement Whenever Feasible and Desirable.

Elements of a Total Program

Views as to what constitutes an adequate approach to problems of mental retardation have changed from time to time. A brief history of Minnesota's program is presented in Chapter II. With increasing experience and research it is clear that no one type of program is adequate. The trend is toward coordinated multiple programs geared to life-long planning, including at least the following elements: 1

¹ Gardner & Nisonger, op, cit.

a. Service Aspects:

(1) Provisions for diagnosis, treatment, and parent counseling.

(2) Programs of training and education.

--Home training

--Nursery classes

--Special education programs during the school-age years including vocational guidance and selective placement in employment for those sufficiently capable to make use of these services.

--Adult education

(3) Programs of vocational (re)habilitation and placement.

--Vocational training centers and sheltered workshops, with programs of training, employment, and selective placement and supervision.

--Social adjustment or occupation day centers for those older adolescents and adults who are unable to profit by training for or placement in employment, either competitive or sheltered.

(4) Day and residential care

--Custodial day care

--Short term residential care

--Long term residential care

--Foster homes, group care homes, boarding homes, half-way houses.

--Institutional Care

- (5) Recreational opportunities.
- (6) Programs for long term supervision and guidance.
- b. Supportive Aspects:
 - (1) Research
 - (2) Training of Personnel
 - (3) Case Finding
 - (4) Public Education

Responsibility for Community Services for The Mentally Retarded

I. Mentally retarded persons are entitled to all the services normally provided to other children and adults.

A. These services should be provided by the governmental body, institution, or private agency that normally provides such services to others.

For example:

1. Education and training should be provided by the public schools.
2. Vocational training and placement should be offered by the Office of Vocational Rehabilitation.
3. Recreation, when provided by a local governmental body, should be extended to the retarded.
4. Camping and religious nurture should be in the hands of non-public institutions and agencies.
5. Pre-school training should be provided by other agencies up to the age when the school's responsibility begins.

- B. There should be a recognition of the excess cost factor in providing public services with reimbursement by the state to the local public body providing such services.

II. Because the retarded have special needs and handicaps, additional services to them and their families must be provided.

- A. All plans for supervision including special living provisions, whether in or out of the home community, should be the responsibility of the Department of Public Welfare and its agents. This would involve additional financial resources to provide supplementary services such as the following:

1. There should be continuing diagnosis and evaluation in order that adequate plans may be made.
2. There must be counseling with parents to help them make realistic plans.
3. There should be provision for long or short term boarding care.
4. Provisions for day care should be made when needed.
5. Sheltered or independent living arrangements should be adequately supervised.
6. Provision should be made for the coordination of services offered by other public and private agencies.

- B. Recognition should be given to the place of private agencies such as Associations for Retarded Children for the part they play in parent education, parent counseling, and services.

APPENDIX C
RECOMMENDATIONS
FROM THE
REPORT OF THE PRESIDENT'S PANEL ON MENTAL RETARDATION*

Research

1. It is recommended that continuous evaluation of scientific personnel policies in Government be undertaken and that salary levels and career satisfactions commensurate with those in similar positions outside of Government be assured. (page 23)

2. The Panel recommends that high priority should be given to developing research centers on mental retardation at strategically located universities and at institutions for the retarded. (page 24)

3. Major national professional associations concerned with research in mental retardation should cooperate in formulating a statement of ethical standards to protect the interests of mentally retarded research subjects. (page 27)

4. The Panel believes that the Secretary of Health, Education, and Welfare should review the requirements for research facilities germane to his Department in the country over the next several years and should prepare a plan for meeting them. (page 27)

* 5. Experimental research findings should be tested in service agencies before widespread application. The Federal and State Governments and private foundations should assist in financing such studies. (page 28)

6. The Federal Government should develop a comprehensive, continuing program for the collection and analysis of population statistics on the incidence, prevalence, and personal and socio-economic characteristics of the mentally retarded. (page 29)

7. In view of the importance of research on basic learning to the achievement of our national goals - and to the special needs of the mentally retarded and those with other disabilities - it is proposed that there be established an Institute of Learning. (page 31)

8. It is recommended that the research budget for exceptional children in the U. S. Office of Education be augmented in accordance with the provisions of legislation proposed in 1962. (page 33)

*** The Panel's recommendations of particular importance for State Comprehensive Planning are marked with a star. The page number in parenthesis refers to the particular page of the Panel's Report on which the recommendation appears.**

9. It is proposed that a number of highly specialized international conferences be organized by the Department of Health, Education, and Welfare to deal in depth with specific research problems underlying mental retardation. (page 36)
10. The Panel endorses and assigns the highest priority to the President's proposals to assist in the construction of academic facilities for higher education and to provide scholarships for students. There is a particularly urgent need for a program with Federal, State, community and private support, designed to prevent the loss to science of large numbers of gifted youth financially unable to enter college. (page 39)
11. Federal financial assistance is urgently needed to increase the capacity of medical schools and to enable capable students to study medicine. The Panel endorses the legislation proposed by the President for this purpose and urges its enactment by the Congress. (page 40)
12. The Panel recommends that the Office of Education, the National Science Foundation, the National Institutes of Health, and private foundations provide an increased number of post-doctoral fellowships, research and career professorships, and awards in fields relevant to mental retardation. Private foundations and national voluntary agencies are urged to increase support of training programs in academic, clinical, and research settings, and to plan with governmental agencies for a more adequate coverage of the need. (page 41)
13. The Panel urges studies to determine what aspects of medical care can be provided by non-medical personnel. The Children's Bureau is urged to expand its interest and support in this direction. (page 42)
14. The National Institutes of Health should be encouraged to continue the development of programs for the training of medical students for research careers. The National Institutes of Health should also develop a program of scholarships and fellowships to qualify individuals who choose to enter a career in medical research through medical education comparable to those which exist for Ph.D. training. (page 43)
15. The graduate fellowship program in the Office of Education should be extended to include provisions for the preparation of research specialists in the education of the mentally retarded. (page 44)
16. Federal fellowship programs should be extended to provide opportunities for students to prepare for research careers in mental retardation in conjunction with training in one of the basic behavioral or social sciences. (page 44)

17. It is recommended that universities offer opportunities for research training in more than one discipline. (page 45)

18. The National Science Foundation, the National Institutes of Health, and private foundations are encouraged to stimulate and support increased research in the process of scientific creativity. (page 45)

Prevention

* 19. The prevalence of mental retardation is significantly higher in those population groups where maternal care is frequently inadequate; therefore, a nationwide program should be launched by the Children's Bureau, the Public Health Service and State and local health departments concentrating on these high-risk groups. (page 50)

* 20. It is recommended (1) that State departments of health and university medical centers collaborate in the development of regional genetic counseling services (by groups of States where possible and appropriate) so that young married couples and expectant parents in all parts of the Nation may have access to such consultation; and (2) that diagnostic laboratories for the performance of complex diagnostic procedures be developed on a regional basis by two or more States. (page 57)

21. The Food and Drug Administration, the National Institutes of Health and the pharmaceutical industry should develop and require the use of techniques for evaluating and assessing the effects of pharmaceuticals on the fetus, infants, and young children. (page 58)

* 22. A few States have enacted laws or established regulations providing for the registration, inspection, calibration, and licensing of X-ray and fluoroscopic machines and other ionizing radiation sources; it is strongly recommended that all states establish such provisions and that the Public Health Service continue to expand its program for the radiological health protection, with special emphasis on the provision of assistance to the States in establishing effective X-ray control programs. (page 59)

23. Hospitals are urged to adopt and use every known procedure for the prevention of prenatal and neonatal defect and brain damage: the joint hospital accreditation board should add criteria for prevention procedures to its present requirements for accreditation. (page 60)

24. In view of the high per cent of automobile and other accidents resulting in brain injury, it is recommended that the accident prevention activities of the U. S. Public Health Service be expanded and that it continue to encourage intensive research in the causes of accidents as a basis of more effective programs of prevention. (page 61)

- * 25. Deprivation of adequate opportunities to learn and other environmental factors may adversely influence the intellectual development of children; therefore communities should undertake programs to modify these conditions. (page 61)
 - * 26. Infants in hospitals and residential facilities may suffer impaired intellectual development as a result of maternal deprivation and lack of stimulation. Officials responsible for such programs are urged to make provision for emotional support and intellectual stimulation as an essential element of care. (page 66)
It is further recommended that accrediting agencies evaluate hospital and residential programs with respect to this important element of child care. (page 66)
 - * 27. As their contribution to a concerted effort of this kind, local and State health and welfare agencies should direct their attention to measures which offset the adverse effects of deprivation on children and youth. (page 68)
28. In view of the critical shortage of personnel and the need for volunteers in health, welfare and education - particularly in areas of extreme deprivation - it is recommended that a domestic Peace Corps be organized to provide stimulus to volunteer community service groups. (page 70)

Clinical and Social Services

- * 29. Because adequate training and care are dependent upon early detection and evaluation, every child should receive continuous child health supervision. Every child should be examined for possible intellectual deviations; screening tests for the early detection of abnormalities should be established as part of the regular and routine service of well-baby and other child health clinics. (page 77)
 - * 30. Every person suspected of mental retardation should have the benefit of expert comprehensive diagnosis and evaluation (page 82)
31. The U. S. Children's Bureau, the U. S. Public Health Service, State health departments, and State and local departments of education should support the extension and improvements of clinical services for the mentally retarded. (page 84)
- * 32. State governments should lift all present restrictions barring retarded children with physical handicaps from services available to other children. To increase the capability of the states to provide services for retarded children under the State Crippled Children's Program, additional earmarked funds should be made available to that program. (page 85)
33. The physical and emotional needs of the retarded are neglected. Adequate treatment of these needs is essential to their total well-being. (page 86)

- * 34. There should be available in every community a "fixed point of referral and information" which provides a life consultation service for the retarded. (page 92)

35. Pilot studies of recreational programs and resources for the retarded should be conducted and the results used as a basis for planning recreational and leisure time provisions for retarded children and adults. (page 96)

Education, Vocational Rehabilitation, Training

36. The U. S. Office of Education should exercise national leadership in the development of educational services for retarded children. (page 102)

- * 37. Specialized educational services must be extended and improved to provide appropriate educational opportunities for all retarded children. (page 103)
- * 38. The 5 areas enumerated below represent particularly urgent needs for extended or new services which should be given emphasis and priority in awarding grants under the extension and improvement program and under the more general education aid programs proposed by the President:

(1) Projects to enrich the learning opportunities of preschool children who live in homes where such opportunities are inadequate.

(2) Instructional materials centers in the special education units of State departments of public instruction or in university departments of education.

(3) State and local community leadership in the development, administration, and supervision of school services for retarded children.

(4) Specialized classroom services to provide for all mentally retarded children.

(5) Services of educational diagnosis and evaluation to provide for early detection of school learning disabilities and to enable appropriate school placement. (pages 105-109)

- * 39. An additional 55,000 trained teachers of the mentally retarded are required. To meet this need, the States, communities, the Federal Government, and private foundations should undertake an extensive expansion of the manpower training programs. (page 111)
- 40. Methods must be developed to provide for more effective training and use of personnel for teaching retarded pupils. (page 114)

41. National standards of teacher qualifications and reciprocal certification agreements must be established. (page 115)
- * 42. There is a need for increased State vocational rehabilitation appropriations which, with their matching Federal grants will produce increased numbers of rehabilitated individuals - including those who were mentally retarded. (page 117)
- * 43. Counseling programs in schools should be strengthened, the testing and employment counseling and placement facilities of the 1,900 employment service offices throughout the country should be fully utilized, and training programs should be used and improved. (page 118)
44. Vocational rehabilitation services for retarded youth and adults should be expanded through special Federal expansion grants under the Federal-State program of vocational rehabilitation. (page 120)
45. A Federal program should be established to provide financial support for construction, equipping and initial staffing of sheltered workshops and other rehabilitation facilities. (page 121)
- * 46. Sheltered work opportunities for the mentally retarded should be extended beyond the traditional workshop setting. (page 122)
- * 47. Methods of providing recreational and therapeutic activity centers to serve severely handicapped adults should be explored. (page 123)
- * 48. National, State and local committees on the coordination of education, vocational rehabilitation, training, and placement services should be organized. (page 124)
- * 49. Staffs of State and private vocational rehabilitation agencies should be augmented by specialists in the rehabilitation of the mentally retarded. (page 126)
- * 50. The vocational rehabilitation training program has proven to be an effective mechanism for increasing the available pool of skilled manpower, and it should be expanded to include -
- (1) increased emphasis on knowledge of the social and vocational adjustment of the mentally retarded in the curriculum for the training of rehabilitation counselors.
 - (2) the training of personnel for workshops after studies to determine the competencies needed.

(3) preparation of personnel in rehabilitation and related professions for research careers. (pages 126-127)

- * 51. Every effort must be made and all available services used to equip and train the retarded and assist them in finding suitable employment. (page 129)

52. The Labor Department should review all of its employment services from the standpoint of needs of the mentally retarded to assure that the needs of these people are receiving the appropriate attention and priority. (page 130)

Residential Care

- * 53. Institutional care should be restricted to those whose specific needs can be met best by this type of service. (page 135)
- * 54. The following objectives for residential care should be considered by boards of private institutions, appropriate authorities of the States, and the Council of State Governments.

(1) Every such institution, including those that care for the seriously retarded, should be basically therapeutic in character and emphasis, and closely linked to appropriate medical, educational, and welfare programs in the community.

(2) Every institution has some unique quality or potential that can be developed for the benefit of the entire field. No institution should be regarded as merely "custodial"; those caring for the profoundly retarded offer unusual opportunities for the application of new methods of treatment and care, and for research.

(3) Diagnosis and evaluation should take place before admission and be followed promptly by treatment when the patient is received.

(4) The institution should extend its services beyond the traditional boundaries of its own campus and reach out to assist the patient and his family before his actual admission; this facilitates visits by parents and friends after admission and is an important factor in early adjustment.

(5) Flexible admission and release policies and outpatient programs similar to those of a hospital or school are essential in meeting the needs of the retarded and their families.

(6) The goal of every residential program should be the elimination or amelioration of as many symptoms as possible and the achievement of independent, semi-dependent or even a sheltered extra-mural life for every person

under care in accordance with his potential. This can be accomplished only by a devoted staff with a variety of professional skills and a competent administration. Both can be rendered impotent, however, without the support and leadership of a competent and interested State department or a board of trustees.

Indoor and outdoor recreation; social activities; programs of physical fitness; opportunities for self-expression through music, painting, worship; and other creative outlets are essential aspects of sound institutional programs.

(7) No child or adult should remain in residential care any longer than necessary. Regular and frequent re-evaluations must be scheduled to reveal any possibilities that may have been developed in his community and to determine whether the individual himself has reached the point where he may profit by some other form of care.

(8) If and when the child or adult is ready for return to the community, adequate resources and services for his support should be made available. It may not be wise or possible for some to return to their own families, hence the importance of developing foster or boarding home placements, or homes for small groups similar to those in several European countries.

(9) Responsibility for the care of persons returned to the community should not be relinquished by the institution until assistance is assured from some other source; efforts should be made to see that community services are made available to him before he leaves.

(10) Many residential populations lend themselves to certain unique research undertakings, particularly of a clinical nature. Continued critical evaluation of the institution program itself requires personnel with a research point of view. It is important, therefore, when the size of the institution and the quality and experience of staff justify it, that research in some form be part of the institution program.

(11) The future of residential care must be viewed in the context of State and regional needs and resources; i.e., more than one State should be included in planning in many instances, as the geographical characteristics and resources of some States are such that they cannot meet the needs alone.

Joint planning and development of interstate facilities is particularly important in providing facilities for such combinations of handicap as the blind and the deaf mentally retarded. There is a precedent for such planning in other fields in the experience of the Southern Regional Education Board and the Western Interstate Commission for Higher Education.

(12) Residence laws offer one of the barriers to easy access to residential care. The Interstate Compact on Mental Health sponsored by the Council of State Governments offers a vehicle which can to some extent overcome this obstacle. Twenty-four States are now parties to the Compact which provides that

residents of these States may be admitted or transferred to an institution in any other party State by common agreement, whenever in the judgment of the Compact administrator the patient's interest will be served thereby. (pages 136-138)

55. Upon presentation of a plan meeting criteria established by the Secretary of Health, Education and Welfare, it is recommended that project grants be provided to the State institutions to upgrade the quality of residential services by (a) augmenting and strengthening programs of residential care through demonstrations and pilot projects and other means designed to establish permanent improvement and change in institutional programs; (b) support of in-service training and education; and (c) support of research projects in institutional settings. (page 140)

56. The Secretary of Health, Education, and Welfare should review the requirements for construction of essential facilities for the mentally retarded under public and nonprofit auspices, including facilities which are not necessarily under direct medical supervision. (page 140)

- * 57. The Panel recommends that local communities, in cooperation with Federal and State agencies, undertake the development of community services for the retarded. These services should be developed in coordination with the State comprehensive plan for the retarded, and plans for them should be integrated with those for construction and improvement of services in residential facilities. (page 141)

The Law and the Retarded

- * 58. Each State should establish a protective service for the retarded in an appropriate State agency. (page 150)
- * 59. Guardianship of the property of a retarded person should be clearly differentiated from guardianship of the person. There may well be a need for the former in cases where the latter is unnecessary, and vice versa. (page 151)
- * 60. We recommend the development of a limited guardianship of the person, with the scope of the guardianship specified in the judicial order. Plenary guardianship of the person should be reserved for those mentally retarded who are judicially determined to be incapable of making adequate routine day-to-day decisions. (page 151)
- * 61. The Court must have at its command a comprehensive clinical evaluation by appropriate personnel drawn from the professions of medicine, psychology, education, and social work. (page 151)

- * 62. There should be periodic review by the courts of the need for continuation of any form of guardianship. In particular, the need for a continuance of guardianship should be reviewed when the ward reaches the age of 21.

In appointing guardians of the person, courts should look first to family members, though not necessarily in the order of formal kinship.

Parents or other guardians should be encouraged to advise the court on choice of successor guardians by testamentary expression of preference.
(page 152)

- * 63. No special legislation is needed when a child is sent to a residential facility for the retarded by his parent or by a properly empowered guardian. (page 152)
- * 64. The judicial hearing now required for commitment to an institution over an adult's objection should also be required whenever a retarded adult is to be admitted to an institution without his clear, voluntary consent, unless a guardian has been appointed whose powers include discretion in this matter. (page 152)
- * 65. There should be judicial review every two years of the need for continued institutional care for all retarded adults, whatever their original type of admission. There should always be a review when a mentally retarded person reaches the age of 21. (page 153)
- * 66. Confessions to crime by mentally retarded persons should be accepted only with the greatest caution - if at all. (page 154)
- * 67. It is recommended that procedures which result in automatic commitment to a mental institution of mentally retarded defendants found incompetent to stand trial should be critically reviewed. (page 154)
- * 68. Following a finding of incompetence to stand trial, mentally retarded persons should be allowed, through an attorney, to raise at a hearing before a judge any defense on the facts or the law, other than a defense based on mental disease or defect precluding responsibility. (page 154)
- * 69. Rules of criminal responsibility should be designed, interpreted and administered to reflect contemporary knowledge of the nature and effects of mental retardation. (page 154)
- * 70. There is an urgent need for new approaches in treatment of mentally retarded criminal defendants - those who have been found not criminally responsible because of mental retardation and those who have been convicted. (page 155)

- * 71. The whole body of law that relates to the condition of mental retardation (whether specifically or by implication) should be reviewed from time to time in each jurisdiction. (page 155)

Public Awareness

- * 72. An expanded program of information and education on mental retardation is essential for the general public and pertinent professional organizations. (page 157)
- * 73. Information and materials on mental retardation should be distributed in a variety of forms to national and local groups. (page 158)
- * 74. The cooperation of mass communications media should be sought as a means of increasing public awareness of mental retardation. (page 159)

75. Films for lay audiences should be prepared to deal with such subjects concerning the retarded as -

(a) The general "story" of the retarded and the need for increased and improved community services.

(b) Special education - what it is and why we need an enriched and expanded program.

(c) Vocational training and vocational rehabilitation.

(d) Recreation for the retarded. (page 159)

76. It is further recommended that filmstrips depicting the highlights of the Panel's recommendations be produced. (page 159)

77. It is recommended that the planning and coordinating committee develop and conduct a national program of public education and interpretation. (page 160)

Organization of Services

78. The Secretary of Health, Education, and Welfare should be authorized to make grants to States for comprehensive planning in mental retardation. (page 164)

- * 79. The governor of each state and his staff should review the array of major services outlined in this report, identify the branch of State government which

is, or should be, discharging each responsibility noted, and assess the extent to which each function should be strengthened. (page 165)

- * 80. Each State should make arrangements, through such means as an interdepartmental committee, council or board, for the joint planning and coordination of State services for the mentally retarded. (page 166)

- * 81. Within each State department with a major concern for mental retardation, there should be a division or bureau to administer services to the mentally retarded or a special consultant with department-wide responsibility for the development and coordination of these services. (page 167)

82. It is especially important that grant-making bodies, public and private, foster cooperation and give priority to support of promising joint enterprises. (page 174)

83. Programs of interdisciplinary training centered on models of service should be developed with Federal, State, and private support. (page 175)

84. When pilot demonstrations have proved successful, the tested models of management, coordinated with training and research, should be created in each of the regions served by the U. S. Department of Health, Education, and Welfare. (page 177)

85. Federal agencies, particularly the Departments of State, Defense, Justice and Labor, should identify their activities affecting the mentally retarded and should seek from the Department of Health, Education, and Welfare whatever expert consultation is required. (page 178)

86. The Department of Health, Education, and Welfare should assess its capabilities to stimulate and support the various relevant components of a comprehensive national program related to mental retardation. (page 183)

87. An ad hoc advisory group representative of recipient colleges and universities should be convened to assist in identifying any self-defeating features of the Federal training assistance programs and to suggest measures which might contribute to improving the supply and utilization of manpower in mental retardation. (page 184)

88. The Department should improve its resources for collecting, coordinating, and distributing quantitative data on the mentally retarded and their specific program needs. (page 185)

89. The Department should give special attention to the use of professional and citizen advisory groups in relation to its program on mental retardation. (page 185)

90. The Department should consistently reinforce the principle and practice of comprehensive planning and coordination at the regional, State, and local levels. (page 186)

91. The Department should extend and develop the principle of joint review and programming, and when feasible joint financing, of grants-in-aid by the several Department of Health, Education, and Welfare agencies when this approach will result in a more comprehensive and unified program. (page 186)

92. The Department's increasing emphasis on comprehensive departmental planning should be reflected at the regional level. (page 188)

93. It is recommended that the Secretary invite each Governor to designate several officers in each State with direct major responsibility for programs for the retarded to represent the State in periodic meetings with the Departmental Committee. (page 189)

94. The Department should extend and improve its efforts to interpret its own and the Nation's activities on behalf of the retarded. (page 189)

95. The Department should improve the coordination of the international aspect of its programs for the retarded. (page 191)

APPENDIX D

Volunteer Leadership and Staff of the National Association for Retarded Children to Whom Inquiries May Be Directed

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APPENDIX E

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PE 8-8691 (817)

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APPENDIX FRegional Offices of the U.S. Department of Health, Education and Welfare

REGION I	120 Boylston Street Boston, Mass. 02116	Mr. Lawrence J. Bresnahan
REGION II	42 Broadway (Room 1200) New York, N. Y. 10004	Mr. Joseph B. O'Connor
REGION III	700 East Jefferson Street Charlottesville, Va. 22901	Mr. Edmund Baxter
REGION IV	50 Seventh Street, N. E. (Room 404) Atlanta, Georgia 30323	Mr. Richard H. Lyle
REGION V	New Post Office Bldg. (Room 712) 433 W. Van Buren Street Chicago, Illinois	Mr. Melville H. Hosch
REGION VI	Federal Office Building 560 Westport Road Kansas City, Missouri 64111	Mr. James W. Doorn
REGION VII	1114 Commerce Street Dallas, Texas 75202	Mr. James H. Bond
REGION VIII	621 Seventeenth Street (Room 551) Denver, Colorado 80202	Mr. Albert Rosenthal
REGION IX	Federal Office Bldg. (Room 447) Civic Center San Francisco, Calif. 94102	Mr. Fay W. Hunter